A guide to the diagnosis and treatment of problems of the pancreas

Hepatobiliary Services
Information for Patients

Liver Pancreas Stomach
The tests that you have had so far show an abnormal area within your pancreas. This booklet is designed as a guide for patients with:

- benign (non-cancerous) problems of the pancreas.
- pre-malignant problems of the pancreas, which may give rise to cancer in the future.
- a very likely (if not confirmed) diagnosis of pancreas cancer.

You may be at any stage in the assessment of your pancreatic disease and therefore not all parts of this booklet will apply to you. This booklet will help you understand more about the pancreas, and the procedures and tests you may need to have. We hope it will answer some of the questions that you and your family may have about what is necessary to diagnose and treat your problem.

If you require any further information or advice, we are here to help and support you through your treatment and/or surgery. Whilst the final diagnosis and treatment may differ from patient to patient, we hope this booklet will provide basic information and answers to commonly asked questions.

The pancreas is a spongy, leaf-shaped gland, approximately six inches long by two inches wide, located in the back of your abdomen. It lies behind the stomach and above the small intestine.

The small intestine has three parts: the duodenum, the jejunum and the ileum. The pancreas is also divided into three parts: the head, the body and the tail.

The head of the pancreas lies surrounded by the duodenum. The body lies behind your stomach, and the tail lies next to your spleen.
The pancreatic duct runs the entire length of the pancreas and it empties digestive enzymes into the small intestine from a small opening called the ampulla of Vater.

Two major bile ducts come out of the liver and join to become the common bile duct. The end of the common bile duct meets the pancreatic duct at the ampulla of Vater and empties bile into the duodenum.

If a tumour or a mass in this area blocks the emptying of the bile, you will become jaundice or yellow in colour and you may have itching.
Function
The major functions of the pancreas are to secrete hormones and enzymes. The hormones insulin and glucagon both regulate blood sugar levels. Pancreatic enzymes help in digestion, especially in fat digestion.

What can go wrong with the pancreas?

The four common conditions that affect the pancreas are:

- Inflammation of the pancreas (pancreatitis).
- Cancer of the pancreas or of the bile duct that runs through the pancreas
- Benign tumours of the pancreas, which may be called “cystic tumours”. Some of these may become malignant over many years.
- Endocrine tumours of the pancreas which are usually benign such as insulinomas, VIPomas and gastrinomas.

The investigations that you undergo are almost the same until we are able to confirm the diagnosis. For some patients, we can only make a certain diagnosis at the time of (or shortly after) their operation.
Pancreatitis refers to inflammation of the pancreas. Pancreatitis can be acute (a sudden episode of inflammation) or chronic (where the pancreas has been replaced by scar tissue). Many patients with chronic pancreatitis will have had previous attacks of acute pancreatitis.

Pancreatitis may be a sign of underlying cancer (rarely) or may mimic the appearances of a cancer. This may be because fluid collections around the pancreas can look similar to cystic tumours of the pancreas. Alternatively, scar tissue around the pancreas, or within the pancreas, may distort its appearance and look similar to cancers of the bile duct or the pancreas.
The organs and tissues of the body are made up of tiny building blocks called cells. Cancer is a disease of these cells. Although cells in different part of the body may look and work differently, most repair and reproduce them in the same way. Normally this division of cells takes place in an orderly and controlled manner but if, for some reason, this does not occur, they may develop into a lump which is called a tumour. Tumours can either be benign (non-cancerous) or malignant (cancerous).

In a benign tumour the cells do not spread to other parts of the body and so are not cancerous.

A malignant tumour consists of cells, which have the ability to spread beyond the original site and, if left untreated, can arise in any part of the body when particular cells begin to multiply more than normal and spread into other tissues.

What is pancreatic cancer?

The cause of pancreatic cancer is not known, although there is a slight association with tobacco. It has been suggested that people who have diabetes are at slightly greater risk of cancer of the pancreas but this has not yet been proven. Cancer of the pancreas is slightly more common in men than women. It arises mainly in older people and is rare below the age of 50.

What causes pancreatic cancer?

Symptoms of pancreatic cancer are often mild and non-specific, such as tiredness, lack of energy, weight loss and vomiting. Cancer of the pancreas most commonly arises in the head of the gland.
This has two effects:

- The cancer can block the bile duct which carries bile from the liver to the intestine. This causes the bile to be retained in the body and results in the skin and whites of the eyes becoming yellow; the skin itches; the urine becomes a dark yellow colour, and stools (bowel motions) became pale. This is known as jaundice but rapidly disappears once the blockage is cleared or bypassed.

- The cancer can block the pancreatic ducts leading to poor digestion, loose motions and weight loss. This can be relieved by clearing the blockage or by giving pancreatic enzyme capsules. Diabetes may already be present in a number of patients before developing the cancer or may become apparent soon after diagnosis or following surgery.

What are the different types of pancreatic cancer?

There are three main types of cancer of the pancreas:

- **Pancreatic ductal adenocarcinoma** is the most common type. This comes from the small ducts of the pancreas. Most often it arises in the head of the gland and a common feature is the development of jaundice. This type of cancer often occurs in individuals aged 60 years or older but it can affect younger people as well.
Cancers of the ampulla of Vater also cause jaundice and they tend to affect older people. These are known as **ampullary adenocarcinomas**.

Distal cholangiocarcinomas are cancers of the bile duct as it runs through the pancreas gland.

Duodenal adenocarcinomas: these are rare cancers which arise from the segment of bowel just next to the pancreas, called the duodenum.
What are cystic tumours of the pancreas?

Cystic tumours of the pancreas refer to growths which have fluid within them produced by the lining of the tumour. In some patients these tumours can turn cancerous.

Depending on their size and position some cystic tumours will require surgery to remove them. Others will require observation with regular CT or MRI scans. Your consultant will discuss this with you and decide how often to undertake surveillance or whether an operation is required.
Endocrine pancreatic tumours are hormone-secreting tumours which are very rare and often difficult to diagnose. The amount of hormone secreting by these tumours vary and some are called non-functioning tumours, because they produce none (or very) little. These tumours are mostly benign, but may require treatment because of the hormones they produce or because of their potential to turn cancerous. There are four main types:

- **Insulinoma** - secretes insulin, the hormone that lowers sugar levels in the blood.
- **Gastrinoma** - secretes above average levels of gastrin, a hormone that stimulates the stomach to secrete acids and enzymes. Gastrinomas can cause stomach and duodenal ulcers.
- **Glucagonoma** - secretes glucagon, a hormone that raises levels of glucose in the blood. These tumours also frequently produce an unusual rash.
- **VIPoma** - secretes vasoactive intestinal polypeptide (VIP) a hormone which stimulates the bowel, leading to severe intermittent diarrhoea and weakness due to the loss of essential salts from the body.
A detailed history, thorough physical examination and blood test often lead to the diagnosis. You will have some and possibly all of these investigations:

**Blood test**
A blood test will be taken to check your general health and also to check how well the pancreas is functioning.

**Ultrasound**
This is a simple, painless and relatively quick investigation, which can be used to obtain a picture of the inside of your abdomen.

Pictures are made using harmless sound waves. The sound waves bouncing back (the echoes) from this area are seen as a picture on a screen. Ultrasound is a convenient and painless way to examine the pancreas, liver, bile ducts and gall bladder.
CT scan

This is a more complex and time consuming than an ultrasound but produces excellent pictures of the pancreas and other organs in your abdomen.

A machine shaped like a huge doughnut is used to take special X-rays. You will lie on a table inside the hole in the “doughnut”. The X-rays are taken as very thin slices through the area of the abdomen.

MRI Scan (Magnetic Resonance Imaging)

An MRI scan is similar to a CT scan, but uses a very strong magnetic field to image the pancreas instead of X-rays.

During the test you will be asked to lie very still on a couch inside a metal cylinder, which is open at both ends. The machines are large and make a noise, which can make some people feel isolated during the procedure. The whole test may take up to an hour. It is completely painless, but lying inside the cylinder may make you feel claustrophobic.
Octreotide scan

This is a highly specialised scan which can give valuable information when assessing pancreatic endocrine tumours. A synthesised hormone which is “tagged” with a radioactive marker (the marker is attached to an artificial hormone which resembles the one that the body naturally produces) is injected into a vein.

The scanner then tracks where this hormone goes after the injection. The radiation is not dangerous and is equivalent to simple X-ray examination.

PET-CT Scan

This is a sophisticated isotope scan which shows up areas of increased activity within the body. A substance which emits a tiny amount of radiation is temporarily attached to oxygen molecules which are taken up by very active tissues.

The activity measured can be from tissues which require a lot of oxygen (such as the heart or brain tissue) or from cancer cells which are growing rapidly. The scanner combines these pictures with anatomical pictures from the CT scan. This gives detailed information about changes in the activity of the organ being examined, as well as where these changes are occurring.
Staging laparoscopy (keyhole surgery)

Keyhole surgery will give your surgeon useful information, and in patients will have likely diagnosis of pancreatic cancer it may tell them how far your tumour has spread; this is called staging. By performing a laparoscopy, your surgeon can decide whether surgery will be the best treatment option for you.

A laparoscopy is a small telescopic instrument with a light at the end for inspecting the inside of the abdomen.

A general anaesthetic is needed and sometimes an overnight stay in hospital. A small cut is made in the abdomen so that the doctor can insert a laparoscope to look at the pancreas and liver.

It is also possible to insert a special ultrasound scanner to look closely at the liver’s bile ducts and the pancreas.
ERCP (Endoscopic Retrograde Cholangio-Pancreatography)

This is a special investigation for taking pictures of the bile ducts and pancreatic duct. It involves inserting a special flexible telescope into the mouth, down the gullet through the stomach, and into the duodenum opposite the opening of the bile duct and pancreatic duct.

Dye is injected into the pancreatic duct and X-ray pictures are taken to see where the problem might lie.

This test is more commonly performed to relieve obstructive jaundice by placing a plastic stent in the bile duct.

Many different types of stents are available. These can either be made of a special plastic or from a non-reactive metal which forms a mesh that expands and holds the bile duct open.
**EUS (Endoscopic Ultrasound)**

This investigation allows the doctors to assess your pancreas. This procedure involves using an endoscope (a long flexible tube) with a special probe that scans the surrounding structures. The probe uses high frequency sound waves to create pictures of nearby structures. As the probe can be placed very close to the organs, the images are very clear and even quite small abnormalities (lymph glands) can be seen and where necessary biopsies can be taken to confirm diagnosis.

This investigation is performed under sedation in the endoscopy department and is generally done without having to stay in hospital overnight afterwards.
Treatments are planned for each person individually, which means that one person may not receive the same treatment as another even though they have the same type of cancer. The best treatment for each person depends on a wide range of factors - the type of the tumour you have, the size and position of the tumour and also the underlying pancreatic disease. Other factors such as general health are taken into account.

The Multidisciplinary Team (MDT)

The team of health professionals looking after you is known as the multidisciplinary team or MDT. The multidisciplinary team meet once a week to discuss the most appropriate treatment for you. A member of the team will then discuss your treatment plan with you. The following people make up the MDT:

- surgeon in charge of your care
- an oncologist
- a radiologist
- a pathologist
- a clinical nurse specialist (key worker)
- a palliative care consultant
- the pancreatic dietitian.

Surgery

Because of the problems and risks in making the exact diagnosis before an operation, sometimes the diagnosis and the treatment are done at the same time in the operating room. This would be discussed with you beforehand.
“Whipple’s” operation (also known as a pancreaticoduodenectomy). This is the most common surgery for cancer of the head of the pancreas. During this operation, the head of the pancreas, gall bladder, duodenum and part of the bile duct are removed. The remaining pancreas, stomach and bile duct are joined up to the intestine, so that bile, pancreatic juices and food are able to flow normally and digestion can take place.

- **Pancreatectomy**. This is removal of the whole of the pancreas.
- **Distal pancreatectomy**. This is removal of the tail and/or body of the pancreas.
Biliary and/or gastric bypass. Sometimes the cancer cannot be removed during the operation because it has spread into surrounding organs and tissue.

In this situation an operation to bypass the cancer and relieve the symptoms that the cancer is causing would be performed.
Chemotherapy

If a cancer is confirmed which cannot be removed by surgery it is often useful to give chemotherapy to slow down the growth of cancer. This type of treatment is known as ‘palliative treatment’.

After the initial treatment, the doctor will want to monitor your progress and it will be necessary to have regular blood tests and ultrasound or CT/MRI scans. The doctor can then tailor the treatment to your needs and deal with any side effects, new problems or symptoms. It also gives you an opportunity to talk about any worries you may have.

Symptom control

If you decide that you would prefer not to have chemotherapy, we will continue to provide appropriate supportive care for you.

This means that we will treat any problems or symptoms that you might have, as they occur. For example if you become jaundiced we may arrange for you to have a stent (tiny tube) inserted or replaced (if you have a previous stent in place) to relieve the jaundice.

With your permission, we will refer you to a Community Macmillan or LOROS nurse, who will be able to manage some of your symptoms when you are at home.
Having surgery

If surgery is appropriate in your case, then the following section of the booklet will explain to you what will happen.

Scheduling your operation

If you are suitable to have surgery, it can usually be scheduled to take place as soon as possible (almost always within four to six weeks).

If you need any additional investigations they will be organised by either your surgeon or clinical nurse specialist. You will need to have pre-admission testing ideally within seven days of your admission to hospital.

What does pre-assessment testing involve?

A nurse will ask you questions, check your blood pressure, pulse and temperature and take routine swabs for MRSA screening. A doctor will complete all relevant documentation and any further tests that need to be carried out. These include further blood tests, a heart recording (ECG) and chest X-ray (to check your lungs).

Consent

You will be asked to give your consent to allow the surgeons to operate on you. Before any operation, make sure that you have discussed it fully with your surgeon so that you understand what is involved. This is the time when you should ask further questions about the risks involved. As with any surgery there are certain risks. There are risks that are associated with the anaesthetic, the surgery and with the recovery. When you sign the consent form you should ensure that you understand clearly what you are signing for.

Anaesthesia for pancreatic surgery

Before your surgery your anaesthetist will visit you. This is the doctor that keeps you unconscious during your operation and looks after all your bodily systems such as breathing and heart function while you have surgery. The anaesthetist will do everything possible to keep you safe during the operation. Before your surgery he/she will ask you questions about your general health and will examine you.
The anaesthetist will explain what is involved with the anaesthetic and will discuss your options for pain relief. You will be asked not to drink or eat anything for eight hours before the operation to ensure that your stomach is empty so that you can be put to sleep with a general anaesthetic.

**The operation**

To enable the surgeon to perform this operation safely, they must be able to see the pancreas clearly. For this reason a large cut (incision) will be made in your upper abdomen under the ribcage. This is known as a roof top incision.

The amount of pancreas removed will depend on the size and location of the tumour. Your surgeon will remove the tumour and the smallest possible amount of normal tissue around it. You will not receive a blood transfusion unless it is absolutely necessary but often it is required during pancreas surgery.

The length of the operation depends on what is found and what needs to be done. It can take between three and five hours. At the end of the operation your surgeon will telephone a relative (or friend) of your choice to explain what was found and what has been done.

The average length of stay in hospital after surgery on your pancreas is ten to fourteen days.

**What are the risks of the operation?**

As with any operation, complications are always possible, some of them serious. With this type of operation, they can include:

- 5% mortality (death) rate related to pancreas surgery. These figures come from worldwide specialist centres
- bleeding
- infection
- leakage from the sutured areas
- pneumonia, heart problems and stroke.
Having surgery (continued)

What should I expect after the operation?

After your operation you will usually wake up in the Intensive Therapy Unit (ITU) or High Dependency Unit (HDU) and spend one or two nights there. This is because after major surgery the doctors and nurses will need to keep a very close check on your bodily functions.

As soon as you are well enough a member of the surgical team will discuss your operation with you in detail.

When you wake up after the surgery you will also have:

- A tube called a nasogastric (NG) tube, in your nose going into your stomach. This tube drains the fluid that naturally accumulates in your stomach. You will have the NG tube for a couple of days and it may be uncomfortable.
- A catheter (a soft, flexible tube) in your bladder to drain urine. This will save you having to get up to pass urine. The catheter is usually taken out after a few days.
- An intravenous (IV) line in a vein in your neck and arm to give you fluids until you begin drinking and eating again.
- Tube drains in your abdomen to remove excess fluid following surgery. The nurses will be regularly measuring the amount of fluid in these drains. The tube drains will be removed within a few days, once they are draining minimal amounts of fluid.

Pain control

It is normal to have pain or discomfort after an operation on your pancreas. You will be given pain-killers (known as analgesia) for several days after the operation to prevent and relieve pain.

Pain relief after pancreas surgery is usually given in the form of an epidural. Epidural analgesia is a method of providing continuous pain relief. The epidural is a fine length of tubing, which is inserted into a small space in your backbone. The epidural tubing is connected to a pump, which automatically delivers pain-relieving medication to you and should give continuous pain relief.
When you wake up from your operation you will be connected to a pump and you will receive your painkiller without the need for you to do anything. You will have pain-relieving epidural for as long as you need it, but most patients’ progress to tablets after a few days. It is very important that your pain is controlled enough to enable you to walk, cough and breathe deeply.

**Physiotherapy**

Soon after your operation you will be helped out of bed to a chair and then encouraged to walk a short distance with help from the physiotherapist or nurse. Walking soon after surgery helps improve circulation, prevents blood clots, and stimulates bowel functions. You will be encouraged to do coughing and deep breathing exercises all of which help to prevent chest infections or pneumonia.

**Your diet**

Once your bowels begin to work again, you will be allowed to drink sips of clear fluids and gradually advance to a normal diet. At first you will not be able to eat the same portions of food you did before the surgery. Many patients lose weight before the operation and during the first couple of weeks after surgery. You will regain the weight slowly as your appetite and capacity for food improves.
Going home

Once you tolerate a normal diet, move your bowels, and show no signs of complications, you will be ready to go home. Your doctor will give you discharge instructions and prescriptions for any medication you need. Your nurse will review these instructions with you. If you need a visit by a district nurse when you are at home, it will be arranged before you leave hospital.

Fatigue

Feeling tired (fatigue) is the most common complaint following pancreas surgery, and is expected. You may need a nap during the day, but try to stay out of bed as much as possible so you will sleep at night. It usually takes six to twelve weeks until your energy levels return to normal.

Decreased appetite

It is common to have a decreased appetite after surgery. Try eating smaller meals that have each of the four food groups (fruits/vegetables, meat/chicken/fish, breads/grains and dairy products).

Alcohol

Alcohol may be consumed in moderation but please check with your doctor before doing so.

Pain relief

At home, you may still have some wound pain, and it may be necessary to take some painkillers. Please remember that some painkillers cause constipation so take extra fluids and fibre in your diet. Also remember to take the pain relief as directed by your doctor.

Numbness

This is normal to have numbness of the skin below the incision because some of the nerves were cut; this sensation will diminish over time.
Exercise and driving

Exercise will help you gain strength and feel better. Walking is recommended. Check with your doctor or clinical nurse specialist before resuming any strenuous exercise. Do not lift anything heavier than 2kg for six weeks. It may be a number of weeks before you are able to drive again. We recommend that you contact your insurance company for advice before starting to drive.

Pancreatic enzymes

You may have been prescribed capsules to help you break down the fats in your diet properly. However, whether you are taking the capsules or not, but notice that you are experiencing one or more of the following, please contact us:

- Excessive wind pains, weight loss, opening of your bowels more than three times per day, or pale, smelly bowel motions that are difficult to flush away.

Please contact your General Practitioner (GP) or ask for advice from your Clinical Nurse Specialist (CNS) if you have:

- Temperature above 38°C
- Redness or leakage from your wound
- Any increase in pain or new pain
- Nausea or vomiting
- Jaundice
- Any new or unexplained symptoms.

Follow-up appointment

Usually your first appointment after your operation should be four to six weeks after you leave hospital. Following this appointment, we will see you every six months up to two years, then every year up to five years, to assess for disease recurrence.

At each visit your surgeon will organise for you to have a scan and blood tests prior to reviewing you.
Contact numbers

**Macmillan Cancer Information Centre**
Osborne Building
Leicester Royal Infirmary
LE1 5WW
Staff will provide you with the information you need, or signpost you to the help and support available locally and nationally.
Opening hours: Monday to Friday from 9.30 am to 4.30 pm
Telephone: (0116) 258 6189
Email: cancerinfo@uhl-tr.nhs.uk
www.leicestershospitals.nhs.uk/cancerinfo

**Leicester HPB Unit**
Leicester Hepatic, Pancreatic and Biliary Disease Unit website: www.hpbleicester.com

**Coping with Cancer**
35 Westleigh Road
Leicester
LE3 0HH
Provides practical and emotional support to those affected by cancer. Services include complementary therapies and counselling.
Telephone: (0116) 223 0055
Website: www.c-w-c.org.uk

**Pancreatic Cancer UK**
A central resource of information on pancreatic cancer for patients and carers
Website: www.pancreaticcancer.org.uk
Leicester Pancreatic Cancer Support Group:
This group aims to support those who have been affected by pancreatic cancer and meets every other month, at a venue close to the Leicester General Hospital. Please contact us for more information.

Macmillan Cancer Support
For information and support from specialist nurses.
Freephone: 0808 808 00 00
Website: www.macmillan.org.uk

Cancerhelp
Ask specialist nurses about anything to do with cancer.
Freephone: 0808 800 4040
Website: www.cancerhelp.org.uk

CORE
The charity for research and information on gut and liver disease.
Website: www.corecharity.org.uk
Research

Research continues throughout the world on the causes, treatments and prevention of liver cancer. Improvements have been made in surgical techniques resulting in successful liver resection and transplantation. There are many promising advances in our knowledge of chemotherapy and new drugs undergoing evaluation. There have been dramatic advances in reducing side effects caused by existing drugs.

Within the Hepatobiliary Unit at the Leicester General Hospital, there are a number of research projects currently underway. At present these are the donation of human tissue for medical research, electrolysis as treatment of liver tumours and the development of a bioartificial liver device (like a dialysis machine containing liver cells) to enable patients with liver failure to be treated.

Your consultant surgeon or research fellow will ask you if you would like to be involved in any of these projects. There is no obligation to take part, but if you are interested your surgeon or clinical nurse specialist will be happy to give you more information.
If you would like this information in another language or format, please contact the service equality manager on 0116 250 2959

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